



Rebuilding lives after **stroke**

Our strategy from April 2019, updated October 2022

Stroke
Association

1. Our strategy

A stroke happens in the brain, the control centre for who we are and what we can do. Every five minutes, stroke destroys lives. Stroke can strike anyone – young, old and everyone in between, at any time. It is one of the leading causes of death and adult disability in the UK.

Stroke causes a wide range of physical and cognitive consequences that can have a sudden and massive effect on people's lives. It can rob people of their movement, vision and ability to communicate, and cause fatigue, incontinence, memory problems, difficulties with problem-solving and depression. Every stroke is different, and many people are able to rebuild their lives in some way. But these consequences, often invisible, last a lifetime and frequently go unaddressed.

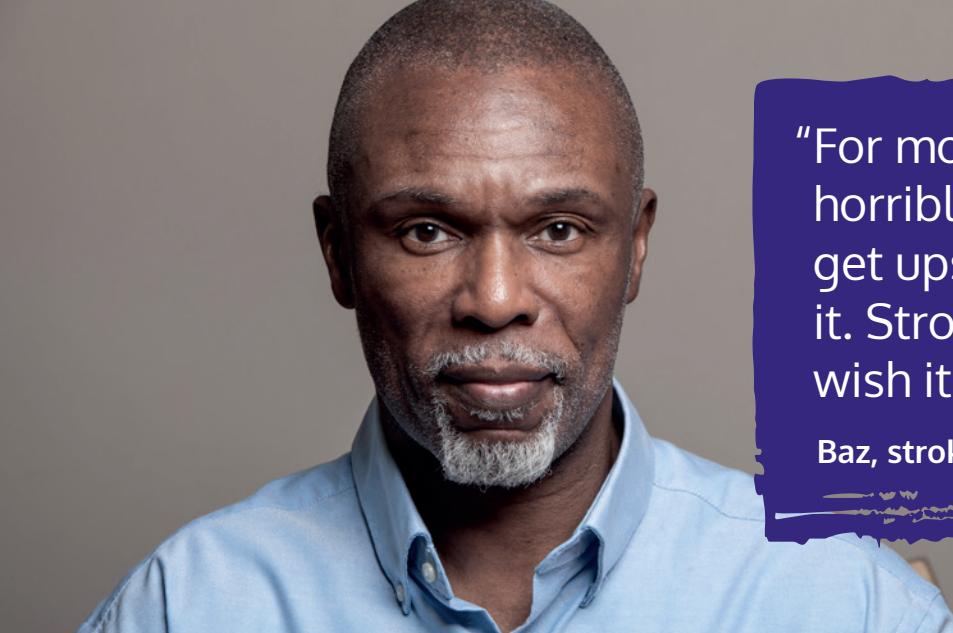
The condition also has a huge impact on the carers, families and friends of stroke survivors. Their lives are often turned upside down and they can struggle with the emotional and practical consequences of providing support. We estimate there are 7 million stroke survivors, carers and family members who are impacted by the consequences of stroke. We refer to these individuals and stroke survivors collectively as "people affected by stroke".

There are over 1.3 million people living with the effects of stroke in the UK. And as our population ages, the number of stroke survivors in the UK will exceed 2 million by 2035. So it's vital that we act to ensure that stroke is better understood and stroke survivors and carers get the support they need now and in the future.

There are significant inequalities in treatment and support depending on where you live and between the four countries of the UK. Stroke is heavily associated with health and social inequalities. And the risk factors for stroke, most notably high blood pressure and irregular heartbeat, are greater among the poorest in society.

"Stroke affects different people in different ways. But I would also like people to understand that it's not their whole self. I'm still a person, still need to work, still have fun, still see my friends. It was just one thing that happened."

Ruth, stroke survivor



"For months afterwards I felt horrible. I wanted to die. I still get upset when I think about it. Stroke is awful, I wouldn't wish it on my worst enemy."

Baz, stroke survivor

Stroke is linked to a range of other complex conditions such as diabetes, vascular dementia, wider heart and circulation conditions and mental health problems. And half of the people who have a stroke also have four or more other long-term health conditions. This is why it's crucial that post-stroke care considers the whole person, not just their stroke, and takes an integrated person-centred approach to their health, care and wellbeing.

We know that 80-90% of strokes are preventable. Rapid diagnosis and treatment are critical to survival and reducing disability. Rehabilitation and long-term support improve physical and emotional health and wellbeing. And an integrated, holistic approach to health and care delivers better outcomes.

Yet stroke outcomes in the UK compare badly to other developed countries around the world. The 2017 Commonwealth Fund rankings on health care outcomes place the UK 10th out of 11 developed countries, in large part due to our poor record on stroke and heart disease.

The economic case for tackling stroke as a priority is compelling. Stroke currently costs the UK economy £27 billion every year. Over half of these costs are borne by informal carers. Without improvements, these costs will treble by 2035. However, there are well-evidenced prevention, treatment and rehabilitation interventions that can significantly reduce the impact of stroke on people's day-to-day lives, and the financial and social burden of stroke on our country.



2. Stroke Association

We're the UK's biggest stroke charity, working across the UK. We're here to support people to rebuild their lives after stroke. We believe everyone deserves to live the best life they can after stroke.

We provide specialist support, fund research, engage with communities and campaign to make sure people affected by stroke get the very best care and support to rebuild their lives.

Making a recovery after stroke is a team effort. We work hard to connect everyone in the stroke community so that people can live the best life possible after stroke.

3. Our vision

Our vision is for there to be fewer strokes, and for people affected by stroke to get the help they need to live the best life they can.

4. Our core purpose

We want to be the trusted voice of stroke survivors and their families. We want to drive better outcomes in stroke prevention, treatment and lifelong support for everyone affected by stroke.

"We want to help stroke survivors and families, and to fund more stroke research. Anytime we do a challenge, we'll try to turn it into a fundraising opportunity. We're also keen to raise awareness about stroke and its risk factors as it's not discussed as much as other diseases, despite having such a devastating impact on people's lives. There are easy things to do to lower your risk, such as monitoring your blood pressure."

Marcia, Fundraiser of the Year, Life After Stroke Awards 2018



5. Our two strategic goals

A. Make stroke the priority it needs to be

Stroke is the fourth leading cause of death in the UK. But it hasn't received the public and political attention it needs – especially when compared to other conditions of equivalent scale and impact, such as cancer and dementia. This has had a considerable impact on stroke treatment and research.

Huge variations in the availability and delivery of stroke treatments across the UK are affecting people's survival and recovery. For example, some stroke centres offer clot-busting thrombolysis to everyone who is eligible, while others aren't able to offer it at all. This means that thousands of people who could benefit from this potentially life-saving treatment go without.

A game-changing clot-removal treatment called thrombectomy could be used to treat up to 10,000 stroke patients a year. Yet in 2021-22, only around 24% of patients in England, Wales and Northern Ireland received the thrombectomy they needed. This means an estimated 76% (6,903) patients who needed a thrombectomy missed out. Access to thrombectomy varies hugely across the UK, causing many cases of avoidable disability.

Stroke research is also under-funded compared to other conditions. Currently the annual funding for stroke research equates to £48 for every stroke patient. This pales in comparison to £241 per person with cancer and £118 per person with dementia. It's imperative that we change this – stroke research is vital in creating the evidence, tools and techniques for future breakthroughs in treatment and care, in turn helping to reduce the personal and economic burden of stroke.

Millions of people across the UK have a connection to stroke, but most don't see it as a cause that needs their involvement. We want these people to understand the scale and impact of stroke. To engage with stroke as a condition, take action to reduce their own stroke risk and benefit from support. And to inspire them to give time, voice and money to the cause.

It's clear that stroke is playing catch-up. But we aim to drive it forward. We want governments, funders and providers in each country of the UK to make stroke the priority it needs to be.

We want to see:

- Ambitious strategies and well-funded improvement plans which rival the best in the world.
- Closing inequality gaps in stroke treatment and outcomes.
- Increased investment in stroke research and capacity, that prioritises research that achieves the greatest impact for people rebuilding their lives after stroke.
- More people connected to stroke giving time, voice and money to rebuilding lives after stroke.



"It's very easy when you have had a huge life-changing event to become lost, bitter and demotivated. That's why it's so important that stroke care is top of the agenda for survivors so they can see they will not just be left, but actually supported, helped and motivated to make a new path for themselves. Everyone, wherever they live, deserves the opportunity to live the best life they can."

Karen, stroke survivor and campaigner

B. Ensure that everyone affected by stroke has access to the rehabilitation and lifelong support they need

One third of stroke survivors feel abandoned when they leave hospital. Many don't have adequate access to quality therapies and rehabilitation, and only one third have a follow-up review. Consequently, stroke survivors and their carers often report high levels of unmet emotional and psychological need.

Stroke survivors are caught in a postcode lottery - where they live determines whether or not they'll receive adequate rehabilitation and support. This could include physiotherapy, occupational therapy, and speech and language therapy, as well as help and advice to get back into education or work, peer support and social activities.

The quality, intensity and promptness of rehabilitation is directly linked to improved outcomes and reduced long-term costs. People supported to make a good recovery are less likely to require welfare support and social care, and less likely to re-enter the health and care system at its most expensive point – in hospital. Inadequate rehabilitation undermines improvements in acute treatments.

We want to see:

- Funders and providers increase investment in research and services for rehabilitation and lifelong support.
- Everyone affected by stroke has the information they need to make informed choices about treatment, care and support which help them to take more control of their ongoing recovery and rebuild their lives.
- A range of emotional, practical and social support offers available in the community for stroke survivors and carers wherever they live.
- Every newly diagnosed stroke survivor benefit from our own support offerings.

"My Stroke Guide helped me to improve my reading, writing and confidence."

Heidi, stroke survivor



"I had wonderful care from the hospital, rehabilitation, the Stroke Association and more. But some are not as fortunate. By involving stroke survivors and sharing different experiences, we're making a real difference!"

Amber, stroke survivor

6. How we make a difference

These are our four important activities through which we make change happen towards our Goal A and B.



System influencing to persuade decision-makers in Government and the health and care system to make stroke a higher priority through well-funded policies and plans, implemented effectively.



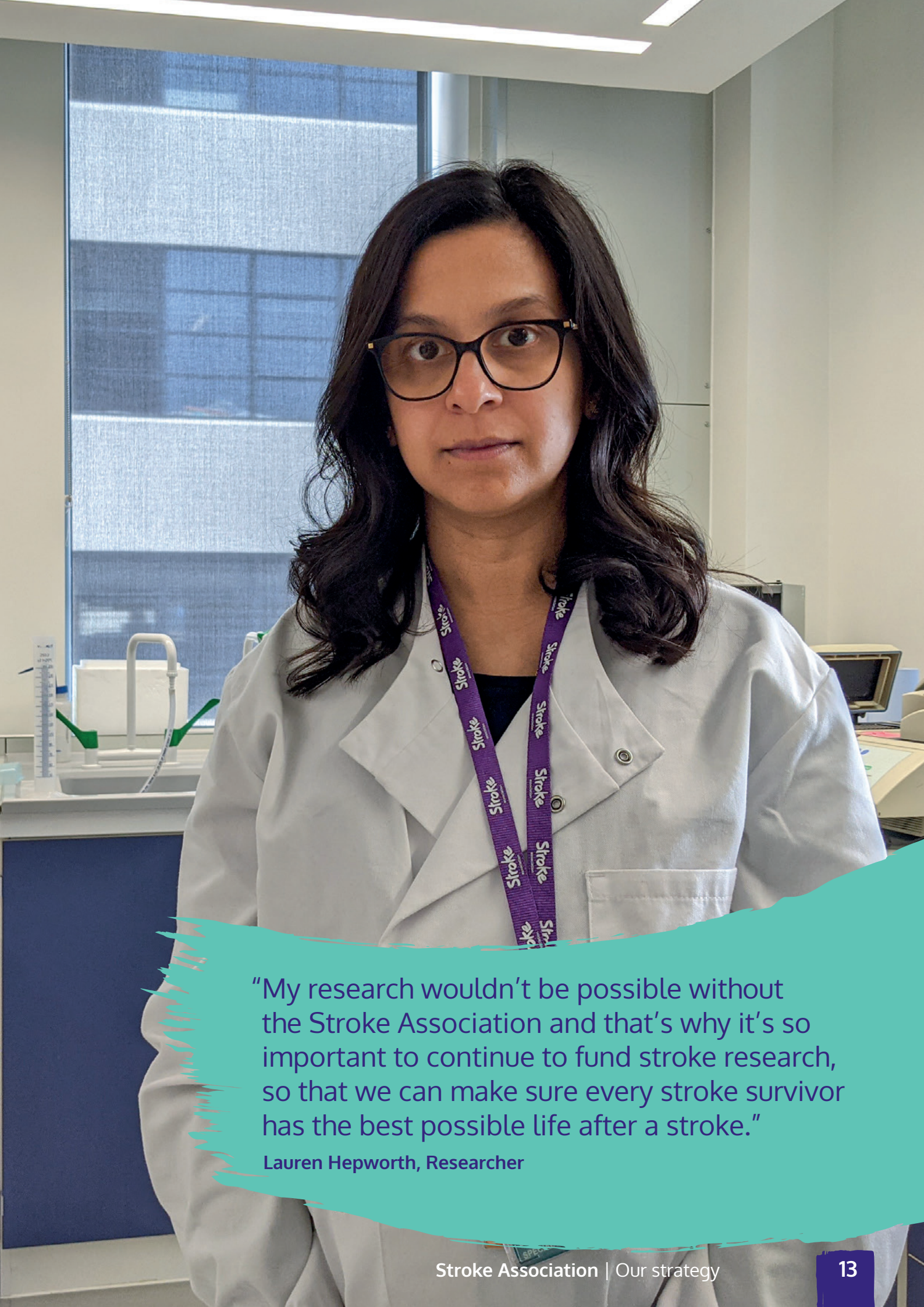
Research to build a community of future stroke research leaders, and through partnership to increase the funding of stroke research in areas that make the greatest difference to people affected by stroke.



Service delivery to provide high quality person-centred support to people affected by stroke that enables them to rebuild their lives after stroke.



Community engagement to listen to and understand the aspirations and priorities of individuals and organisations within communities, building relationships and partnering with them to make positive changes for people affected by stroke within those communities.



“My research wouldn’t be possible without the Stroke Association and that’s why it’s so important to continue to fund stroke research, so that we can make sure every stroke survivor has the best possible life after a stroke.”

Lauren Hepworth, Researcher

7. How we work

Our staff developed a set of **principles** through conversations with stroke survivors, carers, volunteers, colleagues and other organisations. These principles inform and shape our decisions as we implement our strategy.

We work in an environment and are part of a system that's constantly changing, uncertain, and increasingly global in its outlook. Together, our principles set out how we'll adapt and learn, recognising and responding to these complex and changing demands with agility. Our principles are:

"Setting up the group is the best thing I've ever done and has given me a purpose. Without them, I wouldn't be here today."

Trudy, stroke survivor and volunteer



We are stroke to the core

We want people affected by stroke to feel genuinely involved so that they can see the difference they make. Everything we do is informed by people with lived experience of stroke – we strive to genuinely create ideas, actions and decisions together with them. We ensure that we're listening carefully to stroke survivors and carers, and that they're heard by policy makers and opinion formers.

We are in the conversation

We're bold, brave and confident as we make sure that the voice of stroke survivors is always heard. We are expert and equal partners with health, social and political organisations, nationally and locally – the 'go to' people when it comes to stroke. We develop relationships and alliances with partners in the private, public and voluntary sectors who share our vision. We add value through our leadership, expertise, independence, and trusted relationships.

We know how to make an impact

We measure ourselves by the difference we make for people affected by stroke, rather than the work that we do. We know that large impact can sometimes be achieved with relatively small resources. We use data and evidence to inform and evaluate our decisions, actions, service design and delivery. We're a learning organisation that questions, tests, learns, adapts and shares, to improve. And we're transparent about that – holding ourselves and others to account.

We unleash potential

We harness the value and diversity that everyone brings to help deliver our goals – people affected by stroke, ourselves and others. And we fight the inequality that gets in their way. We focus on expertise over position – driving collaboration through cross-functional teams and embedding ownership and accountability at all levels of our charity. We recruit, keep and develop the best people and invest in our culture, skills and knowledge to deliver our goals.

We care for ourselves as for others

We want to be an organisation that excels in kindness, mutual trust and empowerment. This isn't about making allowances and tolerating mediocrity. It's about creating and protecting time and space for the kindness, wellbeing and authenticity that benefits us all. It's about creating the conditions for us to feel safe, supported and challenged to do our best work. Whether that's through small, everyday actions. Or through bigger programmes of change when we need it.

8. Our step changes

From our existing strategy we have chosen **four areas to focus on** to achieve a step change in our impact **over the next three years**.

Step change area	What is our vision?	Why is this so important?
1. Thrombectomy	Thrombectomy is available 24/7 across the UK for all patients who could benefit.	It's a game-changing surgical procedure that retrieves the blood clot causing the stroke from the brain. 10% of stroke patients could benefit from this procedure, but only 2% receive it, and it is a post code lottery as to who does.
2. Newly diagnosed stroke survivors	We are reaching and adding value to the lives of every newly diagnosed stroke survivor.	For most people this is the time at which we can add most value to their lives, yet last year we reached only about 30% of these stroke survivors. We could potentially reach 56,000 more people each year.
3. Awareness	More stroke connected adults have stroke front of mind, and more see the value of the Stroke Association.	Low awareness and understanding of stroke and the Stroke Association make it more difficult for us to give support to people, get support from people, and engage with the health and care system.
4. Income	To achieve sustainable short-term income growth to support current priorities and build the foundations for future transformational growth.	To achieve these step changes and make progress towards our goals we need to substantially increase our income.

9. The difference we want to see

We'll only realise this vision and these goals by working collaboratively across the whole health and care system. We've identified a set of long-term objectives, referred to as system impacts. These can't be delivered by us - or any other single organisation - alone, but we can achieve them together.

We'll consult with our partners about our proposed system impact measures. But as a starting point, these are the impacts that we want to collectively track across the UK and within each nation:

- Reduce the incidence of stroke, taking account of changes in population.
- Reduce the proportion of strokes which are fatal or impact on independence.
- Increase the proportion of people who are able to access appropriate stroke treatment.
- Reduce the self-reported physical, cognitive and emotional impacts of stroke.
- Increase proportion of people helped by the support they receive after a stroke.



When stroke strikes, part of your brain shuts down.

And so does a part of you. That's because a stroke happens in the brain, the control centre for who we are and what we can do. It happens every five minutes in the UK and changes lives instantly. Recovery is tough, but with the right specialist support and a ton of courage and determination, the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

Contact us

We're here for you. Contact us for expert information and support by phone, email and online.

Stroke Helpline: **0303 3033 100**

From a textphone: **18001 0303 3033 100**

Email: helpline@stroke.org.uk

Website: stroke.org.uk

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